

April 27, 2011

Attention: House Appropriations

My name is Tiffiany Leischner. I live in Grand Ledge MI. I first want to acknowledge the committee members and say thank you for the opportunity to speak to you all today. I realize that we are all in very difficult times and that cuts once again have to be made. I realize that there are many programs that benefit many constituents across the state and I respect the position that you are all in. As well as, I have no desire to be in your shoes.

Sometimes I wish that friends, family, professionals, and legislatures could be in our family's shoes. I have a young adult daughter with disabilities. She was three years old before the medical professionals took our concerns seriously and we began our journey. A new and unexpected journey, through the world of disabilities; access to services; being informed; understanding mandates; understanding diagnoses; as well as understanding the difference between treatment and effective treatment.

She was ten years old when I first met with a politician to talk about the challenges we face as a family and the challenges that she faces trying to learn, grow and master independent skills.

I find myself torn between being grateful for becoming a mother to a disabled child in the 90's verses the 50's when she would have went straight to residential. Between having the ability to pay for services she needs and knowing that her services should be coming from the system but can't because of no increase in general funds for a decade and of cuts for the third year in a row. As a mother my number one job and goal has always been to ensure Lindsey has all of the appropriate services that she needs to continue to learn, grow, and gain independent daily living skills. So that hopefully she will be able to be independent someday, have a place of her own, have a life.

Lindsey's father (Rob) and I spend between \$800-1200 a month for services and supports. I have given breakdowns in testimony provided in the past. We accepted when she was younger that we would just have to pay for things not provided by the public systems because after all she is our child. We thought that when she turned 18 that more services would kick in through the system. But Lindsey always seems to be in the "Catch 22" area. Even though Linz was identified as disabled she wasn't identified as "severe" so she couldn't access services through the public mental health system at a young age because she wasn't "severe", we made too much "money" and we had "private insurance". Lindsey's services in the public system would have come through general funds, but general funds haven't increased in the past decade, as well as for the third year in a row it is recommended for the general funds to be cut. We also still don't have "Parity" in Michigan, which meant we couldn't access services through private insurance either. 42 states in the nation have already enacted Parity. I hope that MI will be the 43rd.

It hasn't been easy, but it has been worth it. I don't regret it, I would do it all again in a heartbeat, but things could have been so much easier on us as a family, and financially if we had had the support we needed. Lindsey has always seemed to fit into the "catch 22" area for services. Lindsey is developmentally disabled; she has a full scale IQ of 63. She is autistic (but high functioning), suffers from depression (but is fully stable). I feel compelled to mention that 75% of young adults with developmental disabilities begin to suffer from depression because of experiences they have encountered having a disability and beginning to realize how they are truly different from others.

Linz has always struggled with understanding money, social interactions and life situations. She often misunderstands situations with people that you and I take for granted because it comes so easily, like subtle sarcasm, someone trying to take advantage of her but using a nice tone in their voice, not always knowing yet when to ask questions because she doesn't understand. You and I can do these things very easily as adults, she can't yet. I remember the specialist at three years old explaining to us he wasn't sure if Linz would ever talk and knowing in my gut as her mother that somehow someday she would. I remember being so excited when at 5 when she began talking, at 9 when she made eye contact for the first time, at 13 when she actually made a tear in her eye for the very first time when she was upset.

So we were left in the "Catch 22" area. Rob and I could stop paying 800-1200 a month for services so that she could linger along until reaching the severity criteria area, we could file a lawsuit and spend years battling in court to ensure services for her while wasting precious brain development time. Or we could accept the fact that we will have to wait until Linz is older to buy a house, take a vacation and so on. We decided that Linz is our priority and we will pay 800-1200 a month for services so that she has a shot at independence someday.

But while making the decision and sticking to it all these years I began to speak up and speak out. I try to work with legislatures and professionals (doctors, psychiatrists, teachers, therapists, etc.) to bring a better awareness of the issues faced by families and people with disabilities.

When I think about the history of the disability rights movement in our country it truly baffles me of where we are at.

- In 1975 children with disabilities finally had the legal right to go to school.
- In 1982 a book was published by Knitzer, entitled "Unclaimed Children: the Failure of Public Responsibility to Children and Adolescents in Need of Mental Health". His book drew attention to the plight of children and youth with mental health issues and posited that families needed to be considered a part of the solution rather than identified as the problem.
- In 1986, the Research and Training Center at Portland State University answered his call. They convened the first of several conferences entitled "Families as Allies".
- In 1989, the Federation of Families for Children's Mental Health was formed as the first National advocacy organization. As well as, here in Michigan, the Association for Children's Mental Health (ACMH) was also formed. Both with the focus exclusively on the mental health needs of children and youth.
- In 1990 the Americans with Disabilities Act (ADA) was enacted. This was known as the "Integration Mandate". It requires that public agencies provide services in the most integrated setting appropriate to the needs of the qualified individuals with disabilities.
- In 1999 the U.S. Surgeon General's Report on Mental Health stated "Families support and participation can provide benefits, including reduced need for inpatient treatment, shorter length of stay, better service coordination, and increased likelihood that children will return home following out-of-home placement, and increased caregiver satisfaction".
- Also in 1999, the Olmstead Act occurred. In rejecting the state of Georgia's appeal to enforce institutionalization of individuals with disabilities, the U.S. Supreme Court affirmed the right individuals with disabilities to live in their community in its 6-3 ruling against the state of Georgia in the case Olmstead v. L.C. and E.W.
- In 2002 an important milestone in the evolution of family-driven care was the creation of the New Freedom commission on Mental Health by George W. Bush. The commission was charged with the study of mental health delivery system in America with the goal of making recommendations that would, among other things, enable children with challenges to live, work and participate fully in their communities.
- In 2003 the commission's final report entitled "Achieving the Promise: Transforming Mental Health Care in America" came out. There were six goals identified as the foundation for transforming mental health care in America.

I have no doubt that other things have happened along the way but these were important steps/milestones in our country to recognize and better serve individuals with disabilities. But yet in my shoes, in the shoes of my family sometimes they are pretty words on paper because enacting it all takes money. It baffles me that the ADA was enacted the year my daughter was born and yet the majority of her services wouldn't happen if Rob and I hadn't decided that no matter what she comes first. I think about families like mine that are also in the "Catch 22" area. How long do we have to wait for our kids to get appropriate services? What about the "Catch 22" families that don't have the ability to pay?

I find it ironic that while she falls in the "catch 22" area, we have court orders that state she isn't able to live on her own, doctors' orders that she is required to have 24 hour supervision, she can't go to the college in MI designed for people with disabilities because her full scale IQ is 63 and your IQ can't be under 75 in order to go there. Yes you heard me right there are individuals that are considered too disabled to attend the college in MI that was designed to serve people with disabilities. I

find it ironic that with all the barriers Linz still faces and we face as a family she is only considered mildly impaired and therefore can't be served by the public system.

Governor Snyder has stated that no services will be cut for the disabled, but that isn't reality if the general funds are cut once again. The majority of the disabled population, which is the "catch 22", will be impacted just like they were last year, the year before that, and for the past decade. It is when we don't have all of the facts, or we look away and blindly decide to cut again that we continue the cycle of not serving the ones that need it. We will be responsible as individuals for overlooking the needs of the disabled as a whole. We can no longer serve a "snip it" of the population. Our residents deserve better than that.

"We're in tough times, and we need shared sacrifice from a lot of citizens in our state," Snyder told The Detroit News in an interview while he was in Washington for the National Governors' Association meeting.

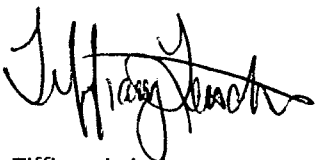
To me "shared sacrifice" means that we all (businesses and individuals) pay our part to balance the budget. We don't give one side over a billion in tax cuts, cut needed services and programs for kids and families across the state and then have families pay more in taxes on top of it. How is that shared sacrifice, how is that fair or equitable?

True tax reform, the general fund and Parity seem to be the answer. I know that Linz is not the only young adult in MI and we are not the only family that faces this issue. This is systemic in MI. The hands of the CMH's are tied because they continue to have less in general funds. No increase in the fund in a decade and cuts the past three years, there will be more individuals with disabilities that aren't served. They won't have access to appropriate services. They won't have access to interventions that lead to successful outcomes. There will be more that end up in the severity range and must be served that ends up costing all of us more in the end.

I hope that by coming today and sharing my thoughts that our legislature will begin to really look at the effects of not invoking fair and equitable tax reform, leading to an actual increase to general fund dollars, leading to at a minimum maintaining funding to our state infrastructure, schools, DHS, and CMH. These cuts have detrimental effects on families across the board, along with individuals with disabilities. I would love to hear our legislatures say enough is enough and were not cutting the general fund again this year, we are going to do what it takes to invoke fair and equitable tax reform, and we're going to look at what we can do to enact Parity.

In closing I respectfully ask that no more cuts be made to CMH general funds. Families and individuals with disabilities aren't accessing services because of this. Please think of families like mine that are in the "catch 22" area when you make your decision. Our kids and constituents of MI with disabilities deserve equality and access to all appropriate services. They deserve a shot.

Sincerely,

A handwritten signature in black ink, appearing to read 'Tiffany Leischner', with a stylized, cursive script.

Tiffany Leischner

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